Shared decision making within goal setting in rehabilitation settings: a systematic review

Rose, Alice; Rosewilliam, Sheeba; Soundy, Andrew

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Title page

Title: Shared decision making within goal setting in rehabilitation settings: a systematic review

Short title: A systematic review considering shared decision-making within rehabilitation settings.

Authors:

Alice Rose[1], Sheeba Rosewilliam[2], Andrew Soundy[3],

Corresponding Author:
[1] Alice Rose, BSc Hons, South Bristol Rehabilitation Centre, 30 Inns Court Green, Knowle, Bristol, BS4 1TF
alice2rose@googlemail.com, 0117 9038392

Additional Authors
[2] Sheeba Rosewilliam, MSc, School of Sport Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham, UK

[3] Andrew Soundy, PhD, School of Sport Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham, UK

Abstract

Objective
To map out and synthesise literature that considers the extent of shared decision-making (SDM) within goal-setting in rehabilitation settings and explore participants' views of this approach within goal-setting.

Methods
Four databases were systematically searched between January 2005-September 2015. All articles addressing SDM within goal-setting involving adult rehabilitation patients were included. The literature was critically appraised followed by a thematic synthesis.

Results
The search output identified 3129 studies and 15 articles met the inclusion criteria. Themes that emerged related to methods of SDM within goal-setting, participants' views on SDM, perceived benefits of SDM, barriers and facilitators to using SDM and suggestions to improve involvement of patients resulting in a better process of goal-setting.

Conclusions
The literature showed various levels of patient involvement existing within goal-setting however few teams adopted an entirely patient-centred approach. However, since the review has identified clear value to consider SDM within goal-setting for rehabilitation, further research is required and practice should consider educating both clinicians and patients about this approach.

Practice Implications
To enhance the use of SDM within goal-setting in rehabilitation it is likely clinicians and patients will require further education on this approach. For clinicians this could commence during their training at undergraduate level.

Highlights

- Currently SDM within goal-setting is limited
- Patients vary in how much involvement they wish to have in goal-setting
- Involvement in decisions about their goals increased patient motivation
- Staff recognised the benefits of this approach however reported various barriers
- Patients and staff need to be further educated about this new healthcare approach

Keywords: shared decision-making, goal-setting, rehabilitation, systematic review

Conflict of interest: None.

1. Introduction

Currently in the UK only 56% of patients are being involved as much as they wish to be in decisions about their care and treatment [1]. In response to this, UK policy makers (including several charities and government sources) are driving healthcare towards an approach, which involves the patient more in the decisions for their rehabilitation care and treatment [2-5]. This process within the context of rehabilitation often takes place within goal-setting [6]. Goal-setting is considered the selection of, and agreement on a behavioural objective, which the patient and team work towards over an identified period of time [7]. Sharing decisions about their goals with patients can have a positive impact on the patient's health and mental well-being [6]. This approach is referred to as shared decision making (SDM) and defined as practice in healthcare where clinicians and patients work together to decide on the best course of action [3]. SDM can take place for example when healthcare professionals encourage patients to discuss their problems and enable them to articulate their goals [7; 8; 9].

SDM, within goal-setting for rehabilitation context, can be best illustrated by adapting the following four characteristics suggested by Charles et al [10]: (1) at least two participants being involved, within rehabilitation settings (this includes the patient and healthcare professional); (2) information is shared by both parties that is relevant to the process, purposes, outcomes and goals of rehabilitation; (3) both parties participate in the decision-making approach, this includes the patient disclosing preferences, both parties asking questions and evaluating the rehabilitation options; (4) an agreement is reached on the goals and how their outcomes will be measured. For the purpose of this article SDM will be considered by goal-setting encounters that contain all four of these elements.

Previous studies have shown that involving patients in decisions about their goals increases patient satisfaction, [10; 11], motivation [12; 13; 14; 15], and creates a greater sense of ownership [16]. However, recent empirical evidence suggests that rehabilitation patients have little involvement in making decisions about their goals [6; 17; 18; 19; 20; 21; 22]. Research reviewing SDM with patients largely focuses on clinical consultations with medical patients [23; 24; 25; 26]. Additionally, recent reviews around goal-setting in rehabilitation did not look at SDM specifically [21; 22] but looked at goal-setting in stroke more generally. Given the above, we identified a need to understand specifically the use of strategies for SDM and its influence on the experience of people involved in goal-setting for wider rehabilitation.

2. Methodology

A systematic review and thematic synthesis was the selected method of qualitative synthesis [27]. The review was undertaken within a subtle realist paradigm [28] where the aim of synthesis was to illustrate different accounts and honour the variability of results from different sources. Within this paradigm we acknowledge the value of existing theory around goal-setting but we did not seek to present a single truth from the results, rather we present a 'truth of truths' [29]. The review was undertaken in three stages; (1) search and identification of literature, (2) critical appraisal of literature, and (3) synthesis of literature. The various techniques adopted in the above stages are described below.

2.1 Stage 1: Search and Identification of Literature

A systematic search [30] for searching and identifying studies was undertaken by the primary author and reported using a PRISMA flow diagram [31]. Searches were sensitive to locate quantitative [30] and qualitative data [32]. Four electronic databases were searched from January 2005 until September 2015 (Cochrane, Medline, CINAHL and ASSIA). The key words were: shared decision-making, decision-making, shared decision, goal planning, goal-setting, care planning, intermediate care, elderly care, rehabilitation and variants of these words using Boolean operators (see supplementary file A for Medline search strategy). Hand searches were conducted on the reference lists of articles included in this review. A second reviewer was involved in the screening of abstracts and agreement by both had to be reached for all included articles.

2.2 Eligibility Criteria

The SPIDER framework (an acronym for sample, phenomenon of interest, design, evaluation, research type) [33] was used to identify the eligibility criteria:

Sample (S): Adult rehabilitation patients. For the purpose of this study, we define rehabilitation patients as those going through an enabling process that helps them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels [34].

Phenomena of Interest (PI): To be included articles had to have considered the SDM approach within the goal-setting process for patients who are undergoing rehabilitation.

Design (D): All types of designs were used including experimental and cohort designs with qualitative analysis, as well as designs, which utilised pure qualitative methods were selected. Reviews were excluded.

Evaluation (E): Both quantitative and qualitative outcome methods were included.

Research type (R): All research types were included, including qualitative and mixed methodologies. Pilot studies were excluded due to risk of conclusions drawn from inaccurate predications from pilot data [35; 36; 37]. In addition to this theses, conference proceedings, and non-peer reviewed articles were excluded because they lacked quality and detail. Articles not written in the English language were excluded because translation facilities were unavailable and selected from 2005 to only include the most recent literature.

2.3 Data Extraction Process

Data was extracted from the articles and inputted into a table (see Table 1). The format of the table was based on a previous systematic review [6].

2.4 Critical Appraisal

Three methods of critical appraisal were undertaken. The quantitative studies (n=5) and the mixed methods study (n = 1) were appraised using an adapted critique tool [6]. This tool was selected for two reasons; (1) due to the heterogeneity of designs used by the included studies, (2) as it has been used to assess quality in a previous review. The tool assesses the presence or absence of 15 methodological considerations (see Table 1 for full details of items).

Semi-structured interview and focus group design studies (n = 8) were appraised using a revised 13-item version of COREQ, rather than the original 32-item [38] because other items have consistently been identified as not sensitive to methodological critique [39; 40]. The tool is split into three domains, (1) research team and reflexivity with five questions; (2) study design with 5 questions; and (3) analysis and findings with 3 questions. The final method of critique for one observational study (n = 1) was the STROBE checklist [41], where items are assessed as present or absent.

Articles were considered for a fatal flaw (a methodological weakness that compromised trustworthiness) [42]. As long as the results were considered trustworthy we included all studies.

2.5 Synthesis

The primary author undertook a thematic synthesis [27] of the data (results or findings) from qualitative studies. Synthesis included three stages [27]: (1) coding of text line by line (2) the development of descriptive themes and (3) the generation of analytical themes and saturation of themes to the minor level where possible. An audit trail of the thematic development can be found in Supplementary File C. Once complete the findings were presented using supportive and critical results from the quantitative studies.

3. Results

3.1 Search Output

The search output identified an initial 3129 studies and 15 articles met the inclusion criteria and were used in the systematic review. This included 5 quantitative studies [9; 11; 17; 43; 44], 9 qualitative studies [12; 13; 14; 15; 16; 18; 19; 20; 45] and 1 mixed methods study [46]. A total of 7 studies were excluded see Supplementary File C for details and reasons. Figure 1 shows a PRISMA flow diagram with the results of the various stages of search and screening process. Table 1 provides demographics and descriptive details of the included studies.

Place figure 1 here

Place table 1 here

3.2 Overview of Methodological critique

No article was considered fatally flawed. With regards to the quantitative and mixed methods studies, the average score was 10/15. Three articles achieved over 70% of the tool's indicators and only two articles [9; 17] achieved less than 50% of the indicators. The average score achieved on the COREQ tool was 7/13. From the quantitative studies identified in the literature review, Tomori et al [9] and Maitra and Erway [17] achieved the lowest score (7/15). Compared to Dalton et al [43] and Turner-Stokes et al [11] who achieved the most indicators on the quality tool. Amongst the qualitative studies, Brown et al [15] and Scobie et al [12] received a particularly low score in quality compared to the other studies. Young et al [18] and Lloyd et al [45] were found to be of higher quality achieving over 69% of the COREQ criteria. The observational study by Schoeb et al [20] achieved 80% of the STROBE criteria. Due to word limits the full and summary details of the critiques undertaken are placed within Supplementary file B.

3.3 Synthesis and Themes

3.3.1 Theme 1. Approaches and methods of SDM within goal-setting in current practice

How goals were set and the level of patient involvement within goal-setting varied amongst the literature. Overall, only three studies reported a goal-setting process with clear evidence for SDM [12;13;16]. Holliday et al [16] and Van de Weyer et al [13] were part of a larger study based in the same neurological rehabilitation unit. This unit and a community rehabilitation team

[12] used a similar approach where patients were given a booklet with tasks designed to identify problems and elicit goals. Patients were given this booklet at the start of their rehabilitation and a goal-setting meeting was subsequently arranged. These studies held the meeting with all team members involved, the patient and their carers/family. All parties decided on the goals together. Staff in the study by Scobie et al [12] additionally completed an action plan for their goals and the patient held a copy.

The other studies were largely therapist-led with minimal evidence of SDM. There were three approaches to goal-setting identified from one study [14] which used e-mail interviews with 15 therapists: therapist controlled goal-setting (4/15), therapist led (10/15) and patient focussed (1/15). Other approaches involving SDM reported are staff organising formal goal-setting meetings involving patients, carers and staff [13; 14; 18] or staff taking an informal approach to discuss goals with patients during therapy sessions [12; 19; 20; 45].

Applying these approaches to the literature, four studies [12; 18; 19; 20] described a therapist-led approach to goal-setting with little evidence of the SDM approach. For instance, two studies [18; 20] identified that the therapist would suggest goals and the patient could agree or disagree perhaps because patients struggled to come up with their own goals despite being encouraged to do so by staff. This resulted in the therapist suggesting goals and the patient could agree or disagree. Additionally, the mind-set of staff to prioritise a list of ‘privileged’ (high priority for the service) goals prior to discussing goals with patients and their family was steering away from SDM [19]. If the patient expressed goals that did not align with the privileged goals, staff would try to steer the patient towards the pre-selected goals, or frequently just ignore the expressed goal. Moreover, they would begin any discussions about goals with statements that indirectly limited the potential scope of goals [19]. Consequently, staff managed the interaction in order to control the process despite the opportunity for patients to participate more in goal-setting.

Within the process of goal-setting various levels of patient involvement were reported [14; 15; 45]. Brown et al [15] and Lloyd et al [45] reported that the level of patient involvement depended on the patient’s wishes. Those patients who wished to be involved in setting their goals were seen as equal partners by the team and jointly set their goals with the clinician. However, those patients who had less desire to make decisions on their goals were happy for the clinician to initiate. Two studies [17; 46] indicated a perceptual gap between staff and patients on involvement in decisions about their goals. In both studies staff reported adopting a patient-centred approach however patients reported having minimal involvement and indicated frustration at not being involved enough.

3.3.2 Theme 2. Staff views on using SDM within goal-setting

All but one study [19] that interviewed staff reported that clinicians could see the benefits of using SDM within goal-setting. Staff valued the input from family and patients in the goal-setting process [14; 18], with one staff member commenting how it felt rude with the patient excluded [14]. Clinicians found it useful to speak to family about the patient's pre-morbid level of functioning and what they felt their relative could achieve [14]. Staff felt a patient-centred approach actively engaged the patient thus facilitating SDM within goal-setting [13].
Despite seeing the benefits of using SDM with patients, staff felt overall it was more effortful (time) compared to the traditional approach [12; 13; 19]. Staff reported that they were under pressure to treat a certain number of patients daily and if they spent longer on goal-setting with one patient, less time would then be available for the patient's rehabilitation [13]. Staff reported wanting more time to get to know their patients to enable them to include patients fully in goal-setting meetings. For example, spending more time with family and finding out what other goals may be important to the patient. One staff member highlighted the amount of overtime they had accumulated due to instigating a patient-centred approach to goal-setting [13]. They reported this was due to the limited number of staff they had and the time constraints they were working with [13].

Only one study reported a staff member with a negative view on using SDM within goal-setting [13]. This study used an entirely patient-centred approach and the staff member found the process too intimate for her patient. She described the patient not being ready to open up and consequently the goal-setting meeting became quite a stifling, closed atmosphere. Ultimately, due to the various reasons discussed above staff reported that some patients just need a more therapist-led approach [15; 18; 20], especially for patients who find it hard to speak up due to lack of knowledge [20] and confidence [18].

3.3.3 Theme 3. Patients views on SDM within goal-setting

Four studies [12; 15; 16; 18] interviewed patients to explore their views on their involvement within goal-setting and responses identified both values and difficulties. Patients reported that they enjoyed goal-setting with clinicians, stating that they felt a sense of ownership of them [12; 15; 16] and personal control over their treatment [12; 46]. Two patients commented how they liked their "tailor-made goals" that were specific to their needs [15; 16]. They found their role as an expert rewarding compared to the "old fashioned situation" [15]. Patients liked thinking about exactly what they wanted to do and achieve whilst in the rehabilitation unit and it helped them constructively think about the future [16]. One patient mentioned that they were quite scared about the future however their goals helped them to cope by breaking it all down [16]. Setting smaller goals was reported as easier compared to looking too far into the future [15]. Patients expressed that they liked being on an equal level as clinicians when setting goals [15; 18]. When SDM was used with patients to set their goals it taught them more about the rehabilitation process [12; 18]. Patients in one study [12] found this useful at the beginning of their

rehabilitation to help guide them. They also found it useful to refer back to their goals to monitor their progress.

The literature described the difficulties patients had regarding participation in goal-setting. Patients from three studies described the difficulties of knowing what they can achieve during their rehabilitation because they had been told their condition was unpredictable [12; 15; 20]. Patients felt the clinician was the “expert” with specialist knowledge, making them in a better position to set goals [15]. Some patients reported being new to goal-setting therefore they did not understand the process and what was expected of them [20]. Overall, compared to usual practice patients were significantly more satisfied with goal-setting with a SDM approach [16; 43; 46].

3.3.4 Theme 4. Perceived benefits of the use of SDM within goal-setting

In addition to the perceived benefits suggested by both staff and patients that were discussed above, other common views suggested by both groups have been discussed below. All studies showed that participants could see the benefits compared to staff setting goals, with the most common benefit reported as an increase in the patient’s motivation [12; 13; 14; 15]. One patient commented that by helping to set his goals he had something to aim for and would not stagnate [15]. Staff agreed that patients who participated in their goal-setting were more motivated to achieve their goals [14].

Three studies considered the effects of patient involvement in decisions about their goals and its effect on functional outcomes [11; 43; 44]. Dalton et al [43] found that patients who were involved in goal-setting had greater improvements in the Barthel index and Functional Independence Measure (FIM). Turner-Stokes et al [11] found similar improvements in the FIM with patients who were engaged in setting their goals. However, Holliday et al [44] found no improvements in the FIM in their group of patients who were more involved in decisions about their goals.

3.3.5 Theme 5. Barriers and facilitators to using SDM within goal-setting

The following theme combines both staff and patient views of barriers and facilitators to using SDM within goal-setting. One of the most commonly reported barriers from the literature was lack of knowledge. For patients this knowledge was in relation to goal-setting, the rehabilitation process and their condition. Consequently, patients felt disempowered to participate [14; 16; 20; 46]. Staff on the other hand felt they did not have the necessary skills to involve patients in decisions about their goals. Physiotherapists from one study [45] felt that these skills came with more experience. The more experienced a therapist was, the better their communication skills were and their ability to empower the patient. Other communication skills such as confidence scaling (a self-report measure of self-efficacy on a 10-point scale), that can facilitate clinicians to use SDM with their patients, are hard to grasp and often time consuming [12]. However, staff emphasised its importance because a patient’s confidence could influence completion of their action plan

[14]. Schoeb et al [20] felt clinicians should be able to seek the patient's preferences and use open questions in their enquiry.

Poor patient motivation was another barrier widely suggested by professionals within the literature [13; 17; 46]. These patients were often referred to as "passive patients". Passive patients are more likely to feel overwhelmed with the task of managing their rehabilitation, misinterpret their role in the rehabilitation process, struggle with problem solving and feel they are unable to have a positive impact on their rehabilitation [47]. Staff described the difficulty of trying to engage these patients in goal-setting because they had never set goals in their lives and were not inclined to [13].

A number of articles described barriers related to the organisation of the healthcare system [13; 14; 17; 18]. Staff discussed the annoyance of varying work patterns (shift work) that resulted in certain staff members not being able to attend goal-setting meetings where patients were present [13; 18]. This resulted in some staff attending the meeting that did not know the patient well enough. They were not familiar with the patient's records and had spent little time with the patient [18]. This was not good for developing a strong staff-patient relationship, a commonly reported facilitator to using SDM [12; 15; 16; 18; 45]. Two studies [12; 18] discussed the benefits of the rehabilitation assistant attending the goal-setting meeting because they had built a strong relationship with them. This could then lead to the patient feeling more confident to express their opinion [18]. Patients from one study reported that when staff brought a list of written goals to the meeting this inhibited discussion [18]. The patients perceived this as a prescriptive action, which demonstrated that staff were uninterested in the patient's opinion.

The use of decision support within goal-setting was a facilitator reported in four articles [9; 12; 13; 14]. Decision support has been defined as different forms of social support (e.g. informational and interactional decision aid, health coaching, encouragement of capability and other forms of information including information packs) from clinician to a patient that enables or facilitates a patient's decision-making and choice so that they can make an informed and empowered decision [3]. For the above articles this included, an electronic patient decision aid [9], the Canadian Occupational Performance Measure (COPM) [14] and a goal-setting workbook [12; 13]. Almost all patients (98%) from one study felt the decision aid enabled them to communicate their hopes and opinions during the goal-setting meeting [9].

3.3.6 Theme 6. How can the goal-setting process be improved to involve patients more?

The most commonly reported improvement suggested by the literature was to introduce an education element prior to goal-setting [15; 18]. Research showed that when asked, patients and carers could not explain the goal-setting process [18]. If they are more aware of what to expect, and for patients what might be expected from them, participation is likely to improve [15; 18].

Research suggests the education session should include information about the patient's condition and recovery outcomes [14]. Some patients felt that an informal discussion with their key worker or therapist prior to the goal-setting meeting would have helped [15; 16]. This was felt to be pivotal in the patient's understanding of the rehabilitation and goal-setting process [16].

Therapists from one article discuss the success of using standard measures [14]. Staff used the COPM with patients to help them identify goals that were important and meaningful for them. The tool aims to assist the patient to reflect on activities of daily living in light of their current condition [14]. Research has shown that standard measures such as COPM increase patient participation in goal-setting and facilitates progression through the rehabilitation process [14].

A final way suggested to improve SDM within goal-setting is to tailor the participation level to each patient [13; 15; 16; 45]. Both professionals and patients felt that when patients were in the early stages of their illness, they preferred less participation in the setting of their goals [13; 16]. Physiotherapists in one study commented that it is important to assess a patient's ability to participate, together with their desire to do so [45]

4. Discussion and Conclusion

4.1 Discussion

4.1.1 Principal findings

To our knowledge this is the first systematic review that has specifically considered SDM within the goal-setting process in rehabilitation settings. The detailed patient views reported in the primary studies is a significant strength of this study. We are also confident that our review gives an accurate representation of current goal-setting practice due to only recent publications (2005-2015) being included.

Within the current analysis only two studies reported an entirely patient-centred goal-setting process with clear evidence for SDM. The other studies were largely therapist-led with minimal evidence of SDM. A previous systematic review [23] has identified that healthcare providers can lack involvement of patients in decisions regarding their care. Clinicians demonstrated few patient involving behaviours with one of the least-observed behaviours being not giving choice to the patient about their preferred level of involvement. This present review has identified the importance of patient choice about their involvement in the SDM process. Some patients expressed the wish to participate in goal-setting and wanted to be seen as equal partners by their clinicians. However other patients, who were often labelled as 'passive' by their clinicians, were happy for the clinician to set their goals. It therefore appears critical that a healthcare professional seeks a patient's preference for involvement in decision-making before goal-setting commences. With this in mind, it is important to note that the perception of

staff regarding the involvement of patients in SDM may be different from the perception identified by the patient, for instance, one negative case in our analysis suggested the processes was too intimate for a patient [13].

Importantly, patients reported a wide variety of benefits from taking part in decisions about their goals including increased confidence and a sense of ownership over the decision-making process and subsequently perceived control over their situation. This could consequently have a positive impact on the patient's rehabilitation, increasing their motivation to achieve the goals that were set. The literature supported this by demonstrating that patients, who were more involved in the goal-setting process, had greater improvements in their function [11; 43]. Further to this similar results have been identified from review-based research [48] investigating the patient-clinician interaction. The findings suggested that when SDM was used during an interaction it led to improvements in affective-cognitive outcomes (e.g. satisfaction, confidence, knowledge). However, improvement in health outcomes was not found [48]. The latter finding was in contrast to the present results that associated SDM with improvements in patient functional scores.

One of the most commonly reported barriers to using SDM within goal-setting is when patients feel they lack the knowledge to participate. The literature showed that patients often saw the clinician as the 'expert' and consequently felt disempowered to participate. In a recent systematic review of patient-reported barriers to SDM [49], this barrier was reported in 29 out of the 44 studies. Interestingly the review also found that if patients recognised the contribution and importance of their own personal preferences, rather than that of technical knowledge, this facilitated SDM [49]. Clinicians can help patients feel more equal and improve participation by decreasing the knowledge gap between them and providing information about their prognosis, goal-setting and SDM. This is further supported by Charles et al's [10] definition of SDM which states the sharing of information (i.e. patient's condition, prognosis and their rehabilitation options) as a key characteristic.

4.1.2 Limitations

Researchers describe the approach of SDM using various terminology therefore although the search was systematic, some articles may have been missed. Due to the unavailability of translation facilities, articles not written in the English language were excluded therefore some useful literature could have been missed.

4.2 Conclusion

The literature showed various levels of patient involvement existing within goal-setting however few teams adopted an entirely patient-centred approach. Evidence suggests the use of SDM within goal-setting can have a variety of benefits including increased confidence and a sense of ownership. Consequently, this can have a positive impact on the patient's rehabilitation, increasing their motivation to achieve their goals. However, at present research suggests that both clinicians and patients require further education about this approach. Clinicians felt they did not have the necessary skills to

involve patients in decisions about their goals. Whereas patients felt they lacked knowledge in relation to goal-setting, the rehabilitation process and their condition and consequently felt disempowered to participate.

4.3 Implications for practice

To enhance the use of SDM within goal-setting in rehabilitation it is likely both clinicians and patients will require further education on this approach. The literature highlighted that younger, less experienced staff were yet to develop these advanced communication skills [45] and those staff who did have these skills found them time consuming to use [12]. Supporting professionals through training in methods for applying SDM in goal-setting must be considered. Additionally, SDM and complementary communication skills could be taught to students at undergraduate level as well as the benefits of patient participation in goal-setting. One study [50] found that providing students with a brief teaching session on SDM, improved their ability, attitude towards, and confidence in SDM facilitation. This study did involve role-play and the intervention would need to be repeated with real patients to see if the results are transferrable.

Increased patient participation in decisions about their goals can occur through several means. Firstly, clinicians should teach patients about their condition and recovery outcomes [14]. Secondly, clinicians need to help patients engage in the process, with literature suggesting the use of advanced communication skills and decision aids [51; 52]. Tools such as electronic decision aids and workbooks were advised to identify patients' problems and elicit goals. Goal-setting workbooks not only help to engage patients more in goal-setting [12; 13] they could also help staff to learn more about their patients, overcoming a commonly reported barrier. Staff in the study that used a goal-setting booklet [13] reported that they were able to get to know the patient early on during their rehabilitation and discuss any pressing issues. Two specific tools to enhance patient engagement also worth considering; include agenda setting [51] and decisional coaching [52]. Decisional coaching is likely to be time and resource intensive however agenda setting requires no additional tools. Agenda setting is advised at the beginning of encounters (e.g. goal-setting meeting) for more information see [53]. Teaching physicians agenda setting (a process used to talk about a patient's problems) has been shown to positively affect the relationship and interaction quality with patients [51].

The organisation of the healthcare system appeared to influence the ability of the healthcare professional to feel able to use SDM. Limited time per patient may also impact on the SDM interaction as patients may not feel that they are known enough by the clinician or do not trust them. One solution to this may be to have a rehabilitation assistant who does know the patient present at goal-setting meetings.

Future research could investigate methods to educate patients on the goal-setting process, SDM and the importance of their involvement. In addition,

SDM and complementary communication skills could be taught to students at undergraduate level as well as the benefits of patient participation in goal-setting. The majority of the primary studies were conducted with neurological patients and within in-patient settings therefore other patient groups should be studied. With the current shift of the UK NHS services from the acute hospital setting out into the community, it is likely more research around SDM and goal-setting will need to be conducted in a community setting to see if the evidence is transferable.

Conflict of interest: none

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References

[1] Care Quality Commission. Inpatient survey 2014. London: Care Quality Commission (2014)

[2] Department of Health. Equity and excellence: liberating the NHS. London: Department of Health (2010)

[3] The King's Fund. Making shared decision-making a reality: no decision about me without me. London: The King's Fund (2011)

[4] NHS England. Five year forward view. London: NHS England (2014)

[5] The Health Foundation. Helping measure person-centred care. London: The Health Foundation (2014)

[6] S. Rosewilliam, C.A. Roskell, A.D. Pandyan, A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation, Clin Rehabil. 25 (2011) 501-14.

[7] Royal College of Physicians. National clinical guideline for stroke. 4th ed. London: Royal College of Physicians (2012)

[8] Department of Health. The national service framework for long-term conditions. Leeds: Department of Health (2005)

[9] K. Tomori, S. Uezu, S. Kinjo, K. Ogahara, R. Nagatani, T. Higashi, Utilization of the iPad application: Aid for decision-making in occupation choice, Occup Ther Int. 19 (2012) 88-97.

[10] C. Charles, A. Gafni, T. Whelan, Shared decision-making in the medical encounter: what does it mean? (Or it takes at least two to tango), Soc Sci Med. 44 (1997) 681-92

[11] L. Turner-Stokes, H. Rose, S. Ashford, B. Singer, Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation, Int J Ther Rehabil. 22 (2015) 210-6.

[12] L. Scobbie, D. McLean, D. Dixon, E. Duncan, S. Wyke, Implementing a framework for goal setting in community based stroke rehabilitation: a process evaluation, BMC Health Serv Res. 13 (2013) 1-13

13] R.C. Van De Weyer, C. Ballinger, E.D. Playford, Goal setting in neurological rehabilitation: staff perspectives, Disabil Rehabil. 32 (2010) 1419-27.

[14] E. Leach, P. Cornwell, J. Fleming, T. Haines, Patient centered goal-setting in a subacute rehabilitation setting, Disabil Rehabil. 32 (2010) 159-72.

[15] M. Brown, W. Levack, K.M. McPherson, S.G. Dean, K. Reed, M. Weatherall, W.J. Taylor, Survival, momentum, and things that make me "me": patients' perceptions of goal setting after stroke, Disabil Rehabil. 36 (2014) 1020-6.

[16] R.C. Holliday, C. Ballinger, E.D. Playford, Goal setting in neurological rehabilitation: patients' perspectives, Disabil Rehabil. 29 (2007) 389-94.

[17] K.K. Maitra, F. Erway, Perception of client-centered practice in occupational therapists and their clients, Am J Occup Ther. 60 (2006) 298-310.

[18] C.A. Young, G.P. Manmathan, J.C. Ward, Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff, J Rehabil Med. 40 (2008) 190-4.

[19] W.M.M. Levack, S.G. Dean, R.J. Siegert, K.M. McPherson, Navigating patient-centered goal setting in inpatient stroke rehabilitation: How clinicians

control the process to meet perceived professional responsibilities, Patient Educ Couns. 85 (2011) 206-13

[20] V. Schoeb, L. Staffoni, R. Parry, A. Pilnick, "What do you expect from physiotherapy?": a detailed analysis of goal setting in physiotherapy, Disabil Rehabil. 36 (2014) 1679-86.

[21] S. Rosewilliam, C. Sintler, A.D. Pandyan, J. Skelton, C.A. Roskell, Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study, Clin Rehabil. 7 (2015) 1-12.

[22] T. Sugavanam, G. Mead, C. Bulley, M. Donaghy, F. van Wijck, The effects and experiences of goal setting in stroke rehabilitation – a systematic review. Disabil Rehabil. 35 (2013) 177-190.

[23] N. Couet, S. Desroches, H. Robitaille, A. Leblanc, S. Turcotte, G. Elwyn, F. Légaré, Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument, Health Expect. 18 (2015) 542-61.

[24] D. Burton, N. Blundell, M. Jones, A. Fraser, G. Elwyn, Shared decision-making in cardiology: do patients want it and do doctors provide it? Patient Educ Couns. 80 (2010) 173-9.

[25] H. Vaillancourt, F. Légaré, A. Lapointe, S.M. Deschênes, S. Desroches, Assessing patients involvement in decision making during the nutritional consultation with a dietician, Health Expect. 17 (2014) 545-54.

[26] W.J. Flierler, M. Nübling, J. Kasper, T. Heidegger, Implementation of shared decision making in anaesthesia and its influence on patient satisfaction, Anaesthesia. 68 (2013) 713-22.

[27] J. Thomas, A. Harden, Methods for the thematic synthesis of qualitative research in systematic reviews, BMC Med Res Methodol 8 (2008) 1-10.

[28] C. Pope, N. Mays, J. Popay, Synthesizing qualitative and quantitative health research: A guide to methods., Open University Press, Berkshire, England, 2007.

[29] M. Weed, A potential method for the interpretive synthesis of qualitative research: Issues in the development of meta-interpretation, Int J Social Res Methodol 11 (2008) 13-28.

[30] J.P.T. Higgins, S. Green (ed). Cochrane reviewer's handbook 5.1.0. The Cochrane Collaboration. http://www.cochrane-handbook.org. 2011 (accessed 08.09.2015)

[31] D. Moher, A. Liberati, J. Tetzlaff, D.G. Altman, Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement, PLoS Med. 6 (2009) 1-6.

[32] R. Shaw, A. Booth, A. Sutton T. Miller, J. Smith, B. Young, D. Jones, M. Dixon-Woods, Finding qualitative research: an evaluation of search strategies, BMC Med Res Methodol. 4 (2004) 1-5.

[33] A. Cooke, D. Smith, A. Booth, Beyond PICO: the SPIDER tool for qualitative evidence synthesis, Qual Health Res. 22 (2012) 1435-43.

[34] World Health Organisation, In: Health Topics: Rehabilitation. http://www.who.int/topics/rehabilitation/en/, 2015 (accessed 01.12.2015)

[35] E. van Teijlingen, V. Hundley, The importance of pilot studies. Social Research Update, 35. http://sru.soc.surrey.ac.uk/SRU35.html, 2001 (accessed 01.12.2015)

[36] S. Suresh, Nursing research and statistics, second ed., Elsevier, India, 2015.

[37] H. Collins, Creative Research: the theory and practice of research for the creative industries. AVA Publishing, Switzerland, 2010.

[38] A. Tong, P. Sainsbury, J. Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, Int J Qual Health Care 18 (2007) 349-57.

[39] A. Soundy, N. Condon, Patient's experiences of maintaining mental well-being and hope within motor neurone disease: A thematic synthesis, Frontiers in Psychology. 6 (2015) 1-13.

[40] A. Soundy, C. Roskell, T. Elder, J. Collett, H. Dawes, 'in press' (2016). The psychological processes of adaptation and hope in patients with multiple sclerosis; a thematic synthesis, Open Journal of Therapy and Rehabilitation.

[41] V. Gallo, M. Egger, V. McCormack, P.B. Farmer, J.P.A. Ioannidis, M. Kirsch-Volders, G. Matullo, D.H. Phillips, B. Schoket, U. Stromberg, R. Vermeulen, C. Wild, M. Porta, P. Vineis, STrengthening the Reporting of OBservational studies in Epidemiology – Molecular Epidemiology (STROBE-ME): An extension of the STROBE Statement, PLoS Med 8 (2011) 1-12.

[42] M. Dixon-Woods, A. Sutton, R. Shaw, T. Miller, J. Smith, B. Young, S. Bonas, A. Booth, D. Jones, Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods, J Health Serv Res Policy. 12 (2007) 42-7.

[43] C. Dalton, R. Farrell, A. De Souza, E. Wujanto, A. McKenna-Slade, S. Thompson, C. Liu, R. Greenwood, Patient inclusion in goal setting during

early inpatient rehabilitation after acquired brain injury, Clin Rehabil. 26 (2012) 165-73.

[44] R.C. Holliday, S. Cano, J.A. Freeman, E.D. Playford, Should patients participate in clinical decision making? An optimised balance block design controlled study of goal setting in a rehabilitation unit, J Neurol Neurosur Psychiatry. 78 (2007) 576-80.

[45] A. Lloyd, A.R. Roberts, J.A. Freeman, 'Finding a balance' in involving patients in goal setting early after stroke: a physiotherapy perspective, Physiother Res Int. 19 (2014) 147-57.

[46] M. Byrnes, J. Beilby, P. Ray, R. McLennan, J. Ker, S. Schug, Patient-focused goal planning process and outcome after spinal cord injury rehabilitation: quantitative and qualitative audit, Clin Rehabil. 26 (2012) 1141-9.

[47] J. Hibbard, H. Gilbert, Supporting people to manage their health: an introduction to patient activation. London: The King's Fund (2014).

[48] L.A. Shay, J.E. Lafata, Where is the evidence? A systematic review of shared decision making and patient outcomes, Med Decis Making. 35 (2015) 114-131.

[49] N. Joseph-Williams, G. Elwyn, A. Edwards, Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making, Patient Educ Couns. 94 (2014) 291-309.

[50] T.C. Hoffmann, S. Bennett, C. Tomsett, C. Del Mar, Brief training of student clinicians in shared decision making: a single-blind randomized controlled trial, J Gen Intern Med. 29 (2014) 844-9.

[51] H.P. Rodriguez, M.P. Anastario, R.M. Frankel, E.G. Odigie, W.H. Rogers, T. von Glahn, D.G. Safran, Can teaching agenda-setting skills to physicians improve clinical interaction quality? A controlled intervention, BMC Med Educ. 8 (2008) 1-7.

[52] D. Stacey, M.A. Murray, F. Légaré, D. Sandy, P. Menard, A. O'Connor, Decision coaching to support shared decision making: a framework, evidence, and implications for nursing practice, education, and policy, Worldviews Evid Based Nurs. 5 (2008) 25-35.

[53] N. Gobat, P. Kinnersley, J.W. Gregory, M. Robling, What is agenda setting in the clinical encounter? Consensus from literature review and expert consultation, Patient Educ Couns. 98 (2015) 822-9.

[54] R.J. Coppack, J. Kristensen, C.I. Karageorghis, Use of a goal setting intervention to increase adherence to low back pain rehabilitation: a randomized controlled trial, Clin Rehabil. 26 (2012) 1032-42.

[55] S. Eloranta, S. Arve, H. Isoaho, I. Aro, L. Kalam-Salminen, P. Routasalod, Finnish nurses' perceptions of care of older patients, Int J Nurs Pract. 20 (2014) 204-11.

[56] K.M. Suddick, L. De Souza, Therapists' experiences and perceptions of teamwork in neurological rehabilitation: reasoning behind the team approach, structure and composition of the team and teamworking process, Physiother Res Int. 11 (2006) 72-83.

[57] V. Schoeb, E. Bürge, Perceptions of patients and physiotherapists on patient participation: a narrative synthesis of qualitative studies, Physiother Res Int. 17 (2012) 80-91.

[58] D.J. Schulman-Green, A.D. Naik, E.H. Bradley, R. McCorkle, S.T.

Bogardus, Goal setting as a shared decision making strategy among clinicians and their older patients, Patient Educ Couns. 63 (2006) 145-51.

Figure 1 A PRISMA flow diagram identifying the output from results

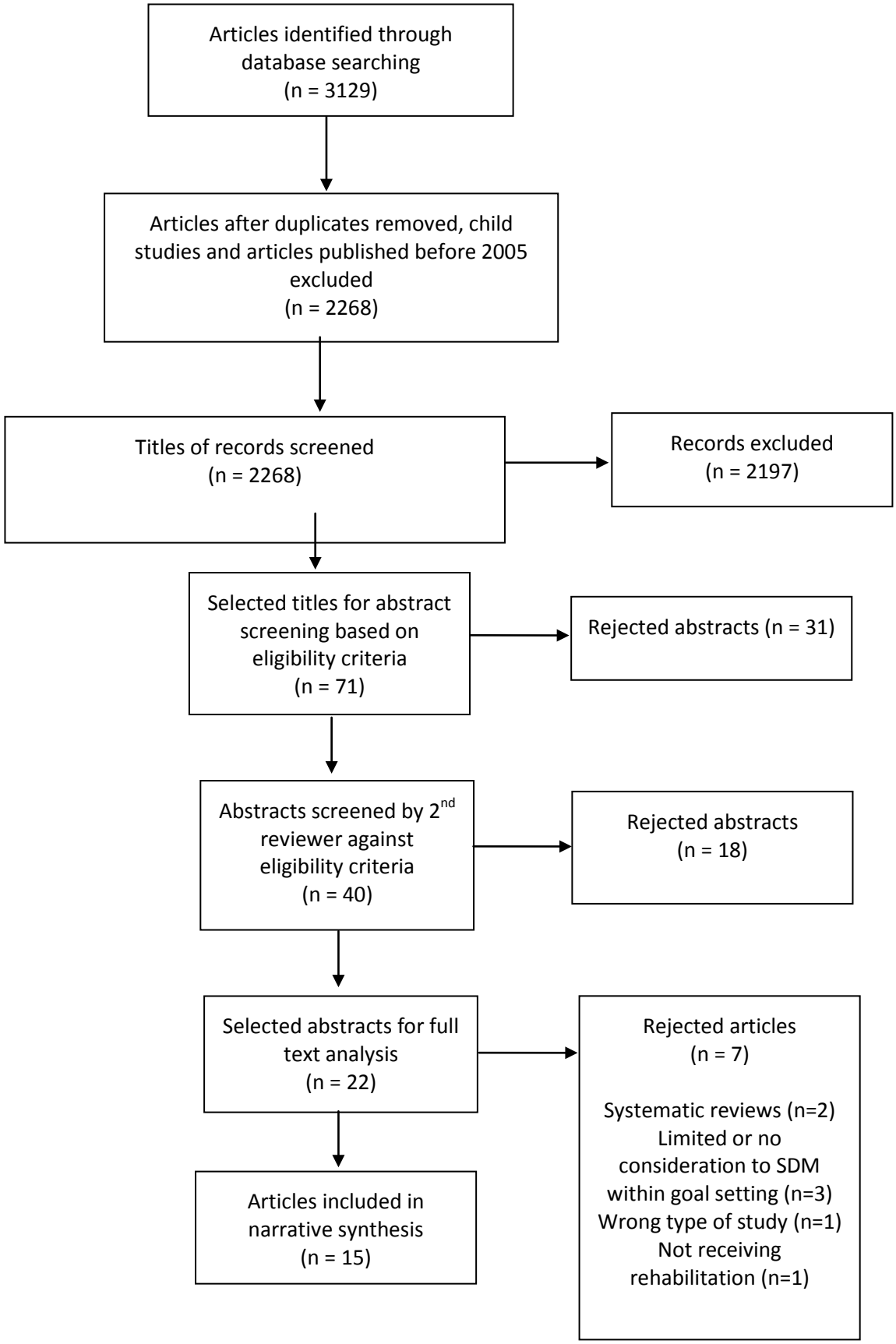

Table 1: Summary table with methodological critique of articles

Study	Setting	Design and Methods	Outcome Measures	Analysis	Findings	Methodological consideration
Hollidaay et al, 2007 [44]	Neurological Rehabilitation Unit - 201 patients recruited	AB optimised balance block design with each block lasting 3 months over 18 month period. Patients were recruited to either phase A = "usual practice" goal setting or phase B = "increased participation" goal setting.	− Patient Participation Scale - Patients' perceptions of the relevance of goal setting − Number, type and outcome of goals − functional ability - Patient satisfaction	Phase A and Phase B compared using student t-tests of mean scores. Mann-Whitney tests on other data	− The majority of phase B reported that they were able to choose own goals compared to A had to agree to team goals. − Goal relevance significantly higher ($p<0.001$) phase B −Phase B set fewer goals −Phase B significantly ($p<0.001$) more satisfied with rehabilitation process −No differences between groups in functional outcomes	Quantitative critique: Items included: 1,2,3,6,9,10,11,13,14,15 Total = 10/15

Dalton et al, 2011 [43]	Regional neurological rehabilitation unit - 105 patient with acquired brain injury	Case controlled retrospective study: compared MDT goals set with patients 12 months before the introduction of new goal setting process (increased patient involvement), with those patients admitted 12 months after.	− Number of goals set and achieved per patient before and after intervention −Barthel index − Functional independence measure	Parametric and non-parametric data was compared using independent samples t-test and Mann-Whitney U-test.	− The intervention resulted in significant ($p<0.008$) increase in number of goals set but not in goals achieved per patient −With the new goal setting process the correlation with change in the Barthel Index strengthened and a correlation was found between goal achievement and functional independence measure change.	Quantitative critique: Items included: 1,2,3,4,5,6,7,8, 9,10,11,13,14, 15 Total = 14/15

Tomori et al, 2011 [9]	Multi-centre study (variety of settings) using convenient sampling.100 patients and 37 Occupational Therapists recruited.	All participants trialled an electronic patient decision aid (ADOC) with their OT to set occupation based goals. Afterwards staff and patients answered 2 questionnaires regarding decision making in the goal setting process.	Likert scale responses to questions.	Descriptive analysis (mean and SD)	− 98% patients agreed or strongly agreed that they were satisfied with their goals set −100% of patients felt their goals set adequately reflected their opinions − 98% of OTs felt they shared the decision-making process with their patients.	Quantitative critique: Items included: 1,2,3,6,11,13,14 Total = 7/15
Turner-Stokes et al, 2015 [11]	Specialist neurological rehabilitation service in UK. 83 adults with neurological disabilities.	A prospective cohort analysis of routinely gathered data over a 1-year period. Examined the relationship between patient/family engagement in goal setting, satisfaction with the process and associated goal attainment and functional gains.	−VAS to rate goal engagement and goal satisfaction −Goal Attainment Scaling −UK Functional Assessment Measure	Non-parametric tests were applied throughout.	− Significant improvements were seen between admission and discharge for patient goal engagement and goal satisfaction. Patient' goal engagement by discharge was strongly correlated with GAS achieved	Quantitative critique: Items included: 1,2,3,4,5,6,7,8,9,10,11,14 Total = 12/15

					T-scores and functional gain.	
Maitra and Erway, 2006 [17]	Adult geriatric care facilities. Convenience sampling - 11 Occupational Therapists and 30 patients	Semi-structured interviews - 20 questions to determine the extent to which patient-centred practice was used.	Questions were designed to elicit responses in a Likert scale format	Descriptive statistics and a one-way ANOVA	The OTs indicated use of principles of patient-centred practice however patients displayed mixed perceptions about their role as active participants. Only a fraction of patients reported assisting in setting goals	Quantitative critique: Items included: 1,2,6,10,11,13, 14 Total = 7/15
Byrnes et al, 2012 [46]	100 Spinal cord injury patients from a specialist spinal injury rehabilitation unit	Mixed methods study considering results from a Clinical Audit of Goal Setting Meetings. The NAC questionnaire was used to measure behavioural indicators at admission and discharge. Patients also completed a 'goal planning questionnaire' upon	Both questionnaires had a likert scale for responses.	Descriptive statistics were computed for both questionnaires. Paired sample t-tests were calculated for the data obtained from the NAC. Pearson's correlational analysis was calculated for the	−1958 goals were established at the first goal planning meeting with 75% achieved by the 2nd meeting. −There was significant improvement on the physical, social, and psychological subscale scores between	Quantitative critique: Items included: 1,2,3,5,6,7,8,1 0,11,13,14 Total = 11/15

		discharge.		data from the goal planning questionnaire. Effect sizes were calculated using Cohen's d. The qualitative component involved a patient focused goal planning questionnaire with likert responses and space for qualitative comments and suggestions.	admission and discharge. −Overall satisfaction with the goal planning process increased when goals were set by the patient	
Holliday et al, 2007 [16]	28 patients were recruited from a Neurological Rehabilitation Unit	Qualitative study using focus groups	Interview schedule explored how patients had experienced two different types of goal setting, "usual practice" and "increased participation in	The recordings were transcribed and interpreted using qualitative thematic analysis.	4 themes were identified which impact on the ways in which these patients made sense of goal setting: The rehabilitation process; personal response to goal setting; previous	COREQ = 7/13 Domain 1: 2/5 Domain 2: 3/5 Domain 3: 2/3

			goal setting".		experience and disease limitations.	
Young et al, 2008 [18]	40 participants (patients, staff and carers) were recruited from a Neurological Rehabilitation Unit. Stratified sampling was used.	Qualitative study using semi-structured interviews were conducted	Interview schedule explored perceptions of goal setting.	Data was analysed with content analysis.	All participants considered goal setting to be beneficial, increasing motivation and providing reassurance to patients and carers. Staff felt goal setting helped them to work collaboratively with patients.	COREQ = 9/13 Domain 1: 4/5 Domain 2: 2/5 Domain 3: 3/3
Van De Weyer et al, 2010 [13]	15 staff (mixed professions) from a Neurological Rehabilitation Unit	Qualitative study using focus groups	Interview schedule explored how staff had experienced two different types of goal	Recorded and the data transcribed and analysed using thematic analysis.	5 themes were identified: the goal setting tools; barriers to goal setting; the keyworker role; patient	COREQ = 6/13 Domain 1: 3/5 Domain 2: 1/5 Domain 3: 2/3

			setting, “usual practice” and “increased patient participation in goal setting”.		characteristics; and the nature of goals.	
Leach et al, 2010 [14]	8 therapists (2 Speech and Language Therapists, 3 Occupational Therapists and 3 Physiotherapists) were recruited from a Geriatric Assessment Unit in Australia.	Qualitative study using semi-structured email interviews	Email interviews were conducted with staff to explore current practices in goal setting.	A framework approach was used for data analysis. This consisted of numerical codes and themes.	3 approaches to goal setting were identified: therapist controlled, therapist led and patient centred. Barriers to a patient centred goal-setting approach largely outweighed facilitators.	COREQ = 7/13 Domain 1: 3/5 Domain 2: 2/5 Domain 3: 2/3
Schoeb et al, 2014 [20]	Observational study of outpatient physiotherapy - 37 patients with musculoskeletal problems recruited.	Observational study using filmed consultations	Observations made to identify how physiotherapists enquire about goals and how patients respond.	Videos analysed using Content Analysis.	In 11 cases physiotherapists enquired explicitly about goals. Problems arose when therapists expected the patient to have a goal in mind.	STROBE = 18/22 No detail considering: (1) eligibility criteria of participants, (2) exploration of variables

					Patient's struggled to state goals due to their knowledge.	and (3) consideration of bias.
Brown et al, 2014 [15]	10 patients with a primary diagnosis of stroke were recruited from 4 hospital based multidisciplinary rehabilitation teams in New Zealand	Qualitative study using semi-structured interviews took place in the patient's home 12 weeks after discharge from hospital.	Interview schedule explored patient experiences of goal setting.	Data was analysed using thematic analysis.	3 key themes emerged. Patients' discourse around goal setting can differ from the discourse conventionally used by clinicians when describing "best practice". Understanding patients' non-conventional views of goals may assist in supporting and motivating them.	COREQ = 4/13 Domain 1: 1/5 Domain 2: 1/5 Domain 3: 2/3
Lloyd et al, 2014 [45]	9 physiotherapists were recruited from 3 stroke units in 3 different NHS Trusts in England (both acute and community	Qualitative study using semi-structured interviews	Interview schedule investigated physiotherapists' perceptions and experiences of collaborative goal setting.	Transcripts were coded and analysed using the constant comparative method of grounded theory.	A provisional grounded theory was constructed, which highlighted that, from the physiotherapists' perspective, collaboration with patients within goal setting early after	COREQ = 9/13 Domain 1: 3/5 Domain 2: 4/5 Domain 3: 2/3

	setting)				stroke involved balance between numerous different drivers, which have the potential to compete. Patient centred goal setting is possible.	
Scobie et al, 2013 [12]	8 patients and 8 staff (2 Occupational Therapists, 2 Physiotherapists, 1 Dietician, 1 Nurse and 2 Speech and Language Therapists) were recruited from a Community Rehabilitation Team in Scotland.	A qualitative study was undertaken using in-depth interviews with patients and staff following the commencement of a new goal setting framework aimed at optimising patient involvement.	Interviews gathered the insights of staff and patients about their experience of this new framework	Interview data were analysed using the Framework approach to thematic analysis.	The Framework was perceived to be both beneficial and broadly acceptable. The framework had a positive effect on goal attainment. Collaborative partnerships between staff and patients were apparent throughout the process.	COREQ = 5/13 Domain 1: 2/5 Domain 2: 0/5 Domain 3: 3/3
Levack et al, 2011 [19]	44 participants (9 patients, 7 family members, 28	Qualitative study using interviews	Study used open-recording of clinical assessments,	The study employed constructivist grounded theory	Certain goals were privileged over others. Involvement of	COREQ = 7/13 Domain 1: 1/5 Domain 2: 4/5 Domain 3: 2/3

	Health Care Professionals) were recruited from 2 inpatient rehabilitation units in 2 separate public hospitals in New Zealand.	therapy sessions and IDT meetings, participant observation and clinical documentation.	to investigate the application of goal setting in inpatient rehabilitation for people with stroke.	patients and family in goal setting resulted in interactional dilemmas when their goals did not align with privileged goals.

Note: *Methodological critique of quantitative studies: 1. Clearly focused question 2. Appropriate design 3. Appropriate sample size 4. Lack of selection bias 5. Lack of performance bias 6. Appropriate intervention 7. Lack of observer bias 8. Lack of Hawthorne effect 9. Reliability of measures 10. Validity of measures 11. Appropriate statistics 12. Lack of cofounding variables 13. Accurate results 14. Clearly presented results 15. Applicability of results*